Chicago Alliance to Fund Retinal Research

SIGHT QUEST NEWSLETTER

Summer 2017

A publication of SEARCH FOR VISION
1011 S. Waiola Avenue, LaGrange, IL 60525 - 847-673-0017 Marla Chorney (Information)
Co-Editors: Lorraine & Jay Popek Advisor: Dr I. Martin Grais

Letter From Dr Pepperberg

Mr. Jay Popek and Ms. Lorraine Popek,
I want to thank you again for the wonderful donation that Search for Vision has made to support work in my laboratory. These funds will be of tremendous help in advancing our research.
We are hopeful that we are on a path that will bring us closer to new therapies for the treatment of age-related macular degeneration and other retinal degenerative diseases. As you noted in the Spring 2017 edition of Search for Vision's Sight Quest Newsletter, our research is focused on two lines of study: the analysis of amyloid-beta in eye tissues, and the development of gold nanoparticle preparations to enable light-sensitivity of retinal ganglion cells. We deeply appreciate Search for Vision's strong encouragement of our work on these two projects.
Again, thanks so much for your generous support
With all best wishes to you and the others at Search for Vision

David R. Pepperberg, PhD

UIC UNIVERSITY OF ILLINOIS AT CHICAGO

David R. Pepperberg, PhD
Searls-Schenk Professor

UIC Eye Center (MC 648)
Department of Ophthalmology and Visual Sciences
Lions of Illinois Eye Research Institute
1855 West Taylor Street
Chicago, Illinois 60612-7243

June 2, 2017

Mr. Jay Popek and Ms. Lorraine Popek
Search for Vision
1011 S. Waiola Avenue
LaGrange, IL 60525
popek@att.net

Dear Jay and Lorraine,

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With all best wishes to you and the others at Search for Vision,

David R. Pepperberg, PhD

Phone (312) 996-4262 • Fax (312) 996-7773 • davipepp@uic.edu

Search for Vision & Parent Petroleum Presents a $5000 Raffle

Raffle tickets are now available.

This raffle is SFV"s longest-lived event and, as in the past, all proceeds are donated to research.

The tickets are $20.00 each or (6) for $100
Drawing will be held Thursday, August 24, 2017
At the:
Parent Petroleum 20th Annual Golf Classic
St. Andrews Country Club
West Chicago, IL 60185

- First Prize $2000
- Second Prize $1000
- Third Prize $550
- Fourth & Fifth Prizes $250
- Sixth, seventh & eighth Prizes $150

(Winner need not be present)

To order tickets:
Make check payable to SEARCH FOR VISION
Mail to
Search for Vision
1011 South Waiola Avenue
La Grange, Illinois 60525

Or Contact: Ann Rasch
Arasch1761@aol.com or 708.354.4620

PARENT PETROLEUM 19TH ANNUAL GOLF CLASSIC

ST. ANDREWS GOLF & COUNTRY CLUB
2241 RT. 59, WEST CHICAGO, IL 60185
AUGUST 24TH, 2017

It is our sincere pleasure to invite you to participate in the Parent Petroleum 19th Annual Golf Classic to benefit Blindness Disease Research. By aligning ourselves with Search for Vision and the Retina Chemical Genomics Laboratory (RCGL), together, we are dedicated to raising awareness of retinal degenerative and other blindness diseases; providing information and community tools to help those coping with vision loss; and to developing the tools required to support a grass roots movement to raise funding for scientific research.

Search for Vision was founded in 2014 by a group of volunteers interested in consciously allocating our hard-earned funds to reputable institutions where common goals and treatments are shared in finding a cure for blindness diseases. In our community, this event helps fund the research team of Dr. Michael Grassi, a dedicated clinical ophthalmologist and researcher at the RCGL of the University of Illinois. The aim of Dr. Grassi's research program is to use genomics in a multi-faceted and interdisciplinary, systems-oriented approach to further drug discovery for common blinding retinal conditions like retinitis pigmentosa. An estimated 93% of all dollars raised go directly to fund laboratory research. This work has significant implications for not only improving the current understanding of the molecular basis of retinal disease, but also for providing critical insights into its treatment.

Millions of Americans are losing their vision facing ultimate blindness. They are our friends, relatives, neighbor and colleagues. This event will help individuals like you to come together and share a common interest in this cause. Please join us this year as a sponsor, individual golfer, or if you can't attend, a financial contribution.
Bear talk hosted by our celebrity guests Ed O'Bradovich former Chicago Bears defensive end and Dan Hampton former Chicago Bears probowler.

Co-Sponsors – BP Fuels BP Castrol
Chairman - Pete Mancini

Board Members

Kelly Aguayo	Chris Peckat
Joe Aliperta	Jay Popek
Donna Combs	Lorraine Popek
Patrick Combs	Mark Potaczek
Ryan Fueling	Ann Rasch
Rita Guenther	Susan Rasch
Rene Grais	Roseann Rossi
Alberta Kosik	Mario Spina
Guy Morgana	

SPONSORSHIP OPPORTUNITIES

Elite Sponsor - $10,000 ACE Sponsor - $5,000 Eagle Sponsor -$2,500

Birdie Sponsor - $1,250 Golf Sponsor - $500 Hole Sponsor - $500

Dinner with Guest - $250 Cocktails & Dinner for two

SCHEDULE OF EVENTS

9:00 am	Registration / Breakfast
10:00 am	Shotgun Start
3:00 pm	Bears Hour / Silent Auction
4:00 pm	Cocktail Reception / Dinner

Putting green & range balls available	Lunch cookout
Gift favors for each golfer	36 holes of golf with electric cart
Hole-in-one prize automobile	All professional services
Full locker room amenities	Dinner reception
Cocktails reception	Silent Auction

Please respond by August 4th, 2017

Make checks payable to: University of Illinois, and include memo Parent Outing
Send to: Parent Petroleum, 3340 W. Main Street, St. Charles, IL 60175-1588
For any additional information, contact Joe Aliperta at 630-584-2509 or
jaliperta@parentpetroleum.com

To Be Donated – CCTV

To be given away. A closed circuit television intensifier with adjustable magnification and selectable black on white or white on black screen. For more details, please call Ann Rasch at 1-708-354-4620 or email to ARasch1761@aol.com.

Research In Brief

FIRST GENE REPLACEMENT THERAPY FOR X LINKED RETINITIS PIGMENTOSA (RP) The first ever gene replacement therapy for X Linked RP took place in March at Oxford Eye Hospital. Professor Robert McLaren the British researcher who pioneered the successful Choroideremia gene therapy in 2016 is also the lead investigator on this clinical trial. He stated "He (the patient) is doing well and now at home, but we will have to wait a few years to know if it has stopped his retina from degenerating." Additional challenges for this trial was that the gene involved, RPGR, is highly unstable, making gene therapy particularly challenging. Professor McLaren's team reprogrammed the genetic code of RPGR to make it more stable, but in a way that does not affect its function. This has allowed the gene to be delivered reliably by a viral vector into the retinal cells. Doctors want to enroll at least 24 more patients in the trial to find out if the technique is safe and effective. patients need to be over 18 years of age, and have a genetic diagnosis of X-Linked RP to be eligible for possible enrolment. This type of RP affects only males and the mothers, who are generally symptom free, carry a gene defect on their X Chromosome. Daughters

of affected males are obligatory carriers as they always inherit an X Chromosome carrying the mutation from their fathers.
. Every clinical trial takes us closer towards therapy.
Source: The Telegraph (UK)

NOVEL APPROACH TO ARTIFICIAL RETINA
Scientists in Italy have developed a retinal implant that can restore lost vision in rats, and are planning to trial the procedure in humans later this year. The implant, which converts light into an electrical signal that stimulates retinal neurons, could give hope to millions who experience retinal degeneration – including retinitis pigmentosa. In retinal degeneration, even when photoreceptor cells are damaged, the retinal neurons around them are largely unaffected. Various types of bionic retinas are being successfully developed that use these intact neural cells to send a neural signal to the visual cortex in the brain.
The Italian implant is made from a thin layer of conductive polymer, placed on a silk-based substrate and covered with a semiconducting polymer. This acts as a photovoltaic material, absorbing photons when light enters the lens of the eye. When this happens, electricity stimulates retinal neurons, filling in the gap left by the eye's natural but damaged photoreceptors. The device has been implanted into the eyes of rats bred to develop a rodent model of retinal degeneration – called Royal College of Surgeons (RCS) rats. Researchers found that the treated rats were very responsive to light at a level of around 5 lux- about the same as a dark twilight sky. The pupillary response of these treated rats was largely indistinguishable from healthy animals. This effect was still evident at six and 10 months after surgery– although all the rats in the tests (including the treated rats, the healthy animals, and the RCS controls) had suffered minor vision impairment due to being older. Based on the results, the team concludes that the implant directly activates "residual neuronal circuitries in the degenerate retina", but further research will be required to explain exactly how the stimulation works on a biological level. While there are no guarantees that the results seen in rats will translate to people, the team is hopeful that it will . "We hope to replicate in humans the excellent results obtained in animal models," says one of the researchers, ophthalmologist Grazia Pertile from the Sacred Heart Don Calabria in Italy. Source Science Alert. See: http://www.sciencealert.com/scientists-have-created-an-artificial-retinaimplant-that-could-restore-vision-to-millions

GENE THERAPY FOR LCA CLOSER TO REALITY
Spark Therapeutics, a gene therapy company has developed the gene therapy for people living with RPE65-mediated inherited retinal diseases. It is currently in the process of completing its biological licensing agreement (BLA) with the U.S. Food and Drug Administration (FDA). If approved, it would be the first gene therapy for any genetic disease to be approved in the United States. The treatment involves delivering a functional copy of a mutated gene directly to the retina. The hypothesis is that this functional copy of the gene produces the necessary protein to slow the progression of disease and restore function in the retinal cells.In clinical trials conducted at the Children's Hospital in Philadelphia (CHOP),

Moorfields Eye Hospital in London, the Universities of Pennsylvania and Florida, and many other centers, more than 100 children and young adults who were virtually blind have had some vision restored. One nine year-old boy has put away his white cane and can now see the blackboard at school. A young woman was able to see fireflies for the first time after receiving the treatment. In the final phase at CHOP, participants between the age of 4 and 44 were better able to complete a mobility course after treatment. The USA Foundation Fighting Blindness funded much of the preclinical research that made these LCA gene-therapy clinical trials possible.

COMPANY LAUNCHES STEM CELL CLINICAL TRIAL

ReNeuron has received authorization from the U.S. Food and Drug Administration to launch a Phase I/II clinical trial of its stem cell therapy. The company is partnering with the Schepens Eye Research Institute, Massachusetts Eye and Ear Infirmary, to develop the treatment. The emerging therapy involves the transplantation of retinal progenitor cells — cells which haven't completely developed into photoreceptors. The therapy may save or even restore vision in people with RP, Usher syndrome, and possibly other retinal diseases. The investigators recently treated their first patient.

CANNABIS CAUTION

A recent study published in JAMA studied the negative effects of regular cannabis use on the ganglion cells in the retina. Their results demonstrated a delay in transmission of action potentials by the ganglion cells in regular cannabis users, which could support alterations in vision. Their findings may be important from a public health perspective since they could highlight the neurotoxic effects of cannabis use on the central nervous system as a result of how it affects retinal processing. Ed- The ganglion cells are a critical layer of cells in the neural pathway that transports messages from the Photoreceptors to the brain.

NUMBER OF AMD GENES DOUBLES

Findings from an international genomics consortium almost double the number of genetic mutations linked to Age Related Macular Degeneration. (AMD). The study, which included 16,144 patients and 17,832 controls, resulted in the identification of 52 associated common and rare mutations in 34 genes. In addition, the consortium claims to have identified the first genetic association specific to wet AMD. Another important fact appears to be that these disease-associated mutations impact on the risk of both wet and dry AMD. So individuals at high risk of choroidal neovascularization may also be at high risk of geographic atrophy. Consequently, therapies that target CNV alone, but not geographic atrophy, may only provide short-erm relief while such patients remain at high risk of developing the dry form of the disease.

PHARMACEUTICAL TRIAL FOR STARGARDT DISEASE

A Phase IIa human study, sponsored by Acucela Inc., based in Seattle, Washington, is recruiting patients to evaluate emixustat hydrochloride in subjects with macular atrophy secondary to Stargardt disease. This experimental small molecule treatment, a visual cycle modulator, will be tested in a multicenter, randomized, blinded study to investigate the pharmacodynamics, safety and tolerability of the drug in Stargardt's patients that meet the designated inclusion criteria. An estimated 30 subjects will be enrolled at clinical sites in the United States. The protocol involves patients taking the study drug orally once daily for one month.

INTERNATIONAL LCA GROUP

Leber Congenital Amaurosis families with a genetic diagnoses of RDH12 are encouraged to join an international LCA patients group. This group consists of families in Europe and the United States whose children have been diagnosed with RDH12 Leber Congenital Amaurosis. They are coming together to support each other and to support the research for a cure to change the children's future. Progress has already been made towards a clinical trial in the (hopefully) near future. A registry of patients with a RDH12 mutation is also being established. If you are affected by RDH12 or you have any questions, please contact Silvia Cerolini : email: silviacerolini@gmail.com Website: www.candleinthedark.eu, Facebook Page: Candleinthedarkfund)

Excerpted from Retinal News – Retinal International, South Africa

Thank You Abby

Michael Popek has replaced Abby Rasch, who updated and maintained our website. Abby is now married and will be moving to England in September. Congratulations Abby and thank you for your help.

Search for Vision Disclaimer

Information disseminated by Search for Vision is for information purposes only. Readers must discuss any intervention with their Eye Care practitioner. Information in this newsletter does not imply that Search for Vision endorses any particular therapy, intervention or medication. Search for Vision assumes no responsibility for the use made of any information provided in this newsletter.

NOTICE

Anyone wishing to receive Sight Quest Newsletter can contact Jay or Lorraine Popek at popek@att.net or call 708-652-4614.